

# 2021 Annual Report



## Contents

President & CEO's Message	1
HDSA Centers of Excellence	2
HDSA Research Grants	4
2021 HDSA Highlights	6
Financials	13

Thank You Donors	16
Planned Giving	IBC
Board of Trustees	IBC
Staff Leadership	IBC
HDSA Contacts & Services	ВС



# President & CEO's Message

#### Dear Friends of HDSA,

After navigating through another year of COVID-19 and moving more events to virtual platforms, HDSA continued push forward to improve the lives of families impacted by Huntington's disease. On top of all the challenges of a pandemic, we received disappointing research news earlier in the year. With all the challenges we faced, the HD Community remained relentless in our fight against HD and we cannot thank our donors and loyal corporate partners enough for their amazing support.

In early 2021, we expanded HDSA's Centers of Excellence program to a record 54 HD care teams with eight satellite sites across the country. We funded five research grants under the Society's largest research initiative, the HDSA Huntington's Disease Human Biology Project. We also awarded two Berman-Topper Family HD Career Development Fellowships, and two Donald A. King Summer Research Fellowships, a vital program to train the next generation of scientists with research expertise in Huntington's disease. For a full breakdown of HD research from this past year, I encourage you to read *The Marker:* HDSA's 2021 Research Report which can be found at HDSA.org/marker21.

For the second consecutive year, the **Annual HDSA Convention** was moved to a virtual event where we welcomed thousands from across the globe. Thanks to the commitment of our speakers, exhibitors and sponsors, as well as the dedicated volunteers who once again ensured that the extraordinary magic of HDSA Conventions was preserved.

Our extraordinary volunteers stepped up in the face of adversity to coordinate creative events that allowed folks to participate in HDSA's mission work in many ways. A prime example is the virtual **Seventh Annual Freeze HD event** held in October that raised more than \$212,000 and generated an enormous amount of awareness thanks to the amazing work of the Freeze HD Committee.

Aside from the events



and fundraising initiatives, the power of storytelling helped HDSA generate more than <u>two billion</u> media impressions — the most ever! During a very 'loud' media year filled with political and health headlines, this meant that HDSA news and Huntington's disease stories reached more people than ever before to educate and motivate them in our work. The fight to continue to raise much-needed awareness continues to be an integral part in educating the world about HD.

One such major news story occurred in July when **Kala Booth** testified in front of Congress to encourage the passage of the **HD Parity Act**. With our most comprehensive push yet to move this crucial bill forward, HDSA volunteers from across the country have come together to contact their local representatives and build momentum for this important bill. From educational and fundraising events to advocacy and awareness, HDSA is able to provide help for today, hope for tomorrow for families affected by HD because of you. Your relentless commitment is ensuring help and hope, until we finally live in a world free of HD. Thank you for your continued support!

With hope,

Aquin Vetr

Louise Vetter President & Chief Executive Officer



# HDSA Centers of Excellence

#### **HDSA Expands Centers of Excellence Network** to 54 Clinics and Adds Eight Partner Sites

In February, HDSA announced that fifty-four outstanding Huntington's disease care facilities were awarded the designation of HDSA Centers of Excellence. In 2021, HDSA awarded \$1,750,000 to the Centers of Excellence network.

The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to providing comprehensive care. The strategic expansion of the HDSA Centers of Excellence network allows expanded access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in Arizona, Arkansas, New Jersey, Mississippi, Ohio and South Carolina, HDSA

now offers care locations in 35 States plus the District of Columbia.

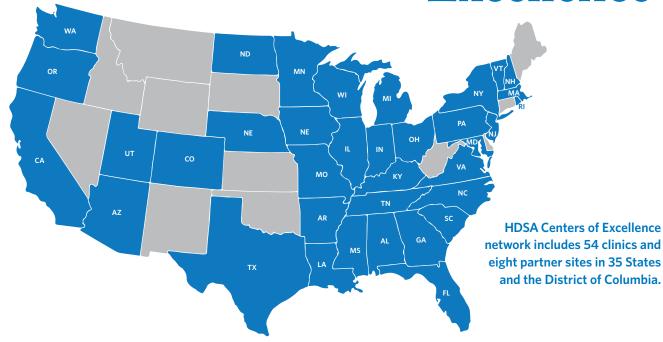
"The expansion of the HDSA Centers of Excellence



program ensures that more families affected by Huntington's disease have increased access to expert and comprehensive care for this devastating rare brain disease," said **Dr.** Victor Sung, Chair of HDSA's National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham. "Additionally, clinical research conducted at many HDSA Centers of Excellence is vital

to the development of potentially life-changing treatments to improve the lives of everyone affected by Huntington's disease."

Learn more about HDSA's Centers of Excellence network, by visiting HDSA.org/coe.





#### HDSA Centers of Excellence Clinical Research Pilot Program

HDSA awarded two grants under the **HDSA Centers of Excellence Clinical Research Pilot Program.** These

grants, totaling \$25,000, represent HDSA's patient-centric research focus by fostering novel clinical research projects within the HDSA **Centers of Excellence network. These** pilot projects will unite scientists with HD families through their direct participation in clinical research. Two clinical research pilot grants were awarded this year.

Deb Kegelmeyer, DPT, at The Ohio State University. This study will evaluate whether telehealth is an effective medium to implement a 12-week movement to music program designed to enhance physical, cognitive, and psychosocial health in adults, as well as whether the intervention leads to changes in these domains.





#### Leonard Sokol, MD,

at Northwestern University, for a study on Meaning-Centered Psychotherapy for treat-



ment of psychosocial symptoms and improved quality of life in persons with Huntington's disease.

## HDSA Research Grants

#### **2021 Human Biology Project Fellowships**

In October of 2021, HDSA awarded five research grants under the Society's largest research initiative, the **HDSA Huntington's Disease Human Biology Project.** Totaling more than \$728,000, these grants represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington's disease



science in the human condition, instead of animal models, with direct participation of people affected by HD. HDSA received impressive applications from researchers all around the world. After careful consideration by HDSA's Scientific Advisory Board, funds were ultimately granted to researchers from the United States, Canada, and Spain.



**Ana Gámez-Valero, PhD** Postdoctoral Research Scientist University of Barcelona

Plasma extracellular small RNAs as early biomarkers of HD and indicators of dynamic changes in disease progression



Tamara Maiuri, PhDResearch AssociateMcMaster UniversityPoly ADP-ribose dysregulation in HDpatient samples and potential for

therapeutic intervention



Joan O'Keefe, PhD, PT Associate Professor Rush University Neural underpinnings of cognitive, balance, and gait deficits in HD



Alby Richard, MD, PhD Assistant Professor and Neurologist University of Montreal

Oculomotor learning as a biomarker in Huntington's disease patients



**Charlene Smith-Geater, PhD** Assistant Project Scientist University of California, Irvine Modulation of E3 SUMO- ligase PIAS1 in 3D

cortico-striatal assembloids and investigation of the HD- relevant CSF SUMO-ome

#### 2021 Donald A. King Summer Research Fellowships

With the goal of attracting the next generation of bright young scientists to HD research and preparing them for the challenges of the field, HDSA established the **Donald A. King Summer Research Fellowship** in 2005 to support undergraduate researchers in their study of biological mechanisms underlying HD pathology. This program was established to honor **Donald A. King,** a tireless advocate for HD families who served as HDSA's Chairman of the Board from 1999 to 2003 before his sudden passing in 2004.

#### 2021 Berman-Topper Family HD Career Development Fellowships

With a shared goal of bolstering opportunities for young HD researchers and generous support from the **Berman and Topper families**, HDSA launched the **Berman-Topper HD Career Development** 

\$160,000 BERMAN-TOPPER FAMILY HD CAREER DEVELOPMENT FELLOWSHIP GRANTS

**Fellowship** in 2016 to support future generations of passionate HD scientists and clinicians. These prestigious fellowships provide \$80,000 of annual funding for three years to young scientists and clinicians who are motivated to make HD a focal point



**Dr. Adys Mendizabal** University of California, Los Angeles Mentor: Dr. Yvette Bordelon

HD epidemiology, healthcare utilization, and outcomes in racially and ethnically diverse populations in the US

Ratnesh Kesineni University of Central Florida Mentor: DR. Amber Southwell



**Russell Wells** Whitworth College Mentor: Michael Sardinia, PhD, DVM



of their long-term career plans. Since its inception in 2016, the program has supported seven emerging scientists in projects that have not only propelled them forward in their careers, but also made significant contributions to the HD research community. This year, after HDSA's Scientific Advisory Board carefully considered proposals from scientists across the globe, the Society was excited to name two 2021 Berman-Topper Fellows, **Dr. Eduardo** 

Silva-Ramos and Dr. Adys Mendizabal.



**Dr. Eduardo Silva-Ramos** Max Delbrück Center for Molecular Medicine Mentor: Dr. Erich Wanker

Characterization and targeting a novel HTT interacting E3 ligase protein complex

## 2021 HDSA Highlights

#### Dr. Jeff Carroll & Dr. Beth Hoffman Join HDSA's National Board of Trustees

"On behalf of HDSA's Board of Trustees, we are excited to welcome Dr. Carroll and Dr. Hoffman" said HDSA's President and CEO Louise Vetter. "They are both established scientific and volunteer leaders in the HD community whose experience will undoubtedly strengthen HDSA's mission work."

For more information about HDSA's National Board of Trustees, please visit www.HDSA.org/bot

#### HDSA Partners With PatientsLikeMe®

The world's largest integrated community, health management, and real-world data platform PatientsLikeMe (PLM) announced in June 2021 that it partnered with the Huntington's Disease Society of America to launch a virtual community for those living with Huntington's disease and for those caring for individuals living with HD. This tailored community will focus on education and peer-to-peer knowledgesharing. This community will serve as a catalyst to expand researchers' knowledge of the condition through the analysis of patient-generated data.

"Partnering with PatientsLikeMe is an exciting new step in our work to help families affected by Huntington's disease come together to support one another, find vital resources and share their journeys so that



Jeff Carroll, PhD



care for HD improves as quickly as possible," said **Louise Vetter,** President and CEO of the Huntington's Disease Society of America.

To access the platform, visit HDSA.org/PLM



#### 31 Days, 31 Stories

Sharing personal experiences is crucial in educating people about the impact HD has on individuals and families.

Videos featuring members of the HD community sharing their narratives have been posted on HDSA's YouTube channel in HDSA's **31 Days, 31 Stories** series.

#### **HDSA Reintroduces HD Parity Act**

In March 2021, the Huntington's Disease Society of America announced that **Senators Kirsten Gillibrand** (D-NY) and Dr. Bill Cassidy (R-LA), along with Representatives Adam Kinzinger (R-IL) and **Bill Pascrell, Jr** (D-NJ) have reintroduced the Huntington's Disease Parity Act (S 868 / HR 2050). The HD Parity Act will waive the **HD PARITY** two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI).

To learn more please visit HDSA.org/takeaction.





Sen. Kirsten Gillibrand (D-NY) Sen. Bill Cassidy (R-LA)





Rep. Adam Kinzinger (R-IL)

Rep. Bill Pascrell, Jr (D-NJ)

#### May Is HD Awareness Month — #LetsTalkAboutHD

May Is HD Awareness Month, so #LetsTalkAboutHD! HDSA teamed up with members of the HD community to turn up the global volume to let the world know about this devastating brain disorder.



#### Kala Booth Testifies in Front of Congress

The Huntington's Disease Society of America applauded the House Energy and Commerce

### **PASS THE**

ACT

Subcommittee on Health for holding a vitally important hearing on July 29<sup>th</sup> that put a spotlight Huntington's disease. Kala Booth, an HD patient



and caregiver, testified to the distinct challenges of living with HD, its multi-generational impact, and the importance of improving access to vital health benefits as outlined in the bipartisan Huntington's Disease Parity Act.



On July 29th, the House Energy and Commerce Subcommittee on Health heard the testimony given remotely by HD patient and caregiver, Kala Booth (above) on the importance of the HD Parity Act.



#### #GivingTuesday — November 30<sup>th</sup>



With more than 250 donations from around the world, more than \$99,000 was raised to support HDSA on Tuesday, November  $30^{th}$ , **#GivingTuesday** — a global day of giving. **This was the most funds raised for an HDSA Day of Giving ever!** 

#### **Scott Porter Invitational: HeroClix for HD**

CTOR SCOTT PORTER PARTNERED WITH WIZKIDS AND HOSTED THE HEROCLIX FOR HUNTINGTON'S VIRTUAL EVENT IN MAY WHICH RAISED MORE THAN \$30,000 TO SUPPORT THE FIGHT AGAINST HD!



### **HDSA Films**

In 2021, HDSA produced four inspiring films featuring HD families. Watch them today on HDSA's YouTube Channel.

- **1** The Dohertys: Finding the Funny
- **2** The Osborns: Our Legacy
- **3** The Osborns
- 4 My Father, My Hero



### Simi Fehoko Wears HDSA Cleats During the NFL's #MyCauseMyCleats Campaign

Dallas Cowboy **Simi Fehoko** supported the fight against HD by wearing custom HDSA cleats during the **NFL's #MyCauseMyCleats** 

**Campaign** during a game against the New Orleans Saints on December 2<sup>nd</sup>. Simi, who comes from an HD family, paid tribute to his grandmother who passed away from HD. This marks the second time an NFL player wore cleats to raise



awareness of HD. **Aaron Donald** of the Los Angeles Rams participated in the initiative in 2018. Thank you Simi! And congrats for the win over the Saints!





#### HDSA Founder's Day — September 18th

Each year, HDSA honors Marjorie Guthrie's legacy to **"do something"** during the **HDSA Founder's Day** campaign on September 18<sup>th</sup>. In 2021, the initiative raised more than \$32,866 to ensure that our social workers, support groups, education programs and critical HD research continue to help improve the lives those affected by HD.



#### **Ginny & Georgia Reunion**

With help from HDSA's dear friend **Scott Porter**, the castmates and creators of the hit Netflix series, *Ginny & Georgia* participated in a virtual reunion fundraiser for HD. The much-anticipated event raised nearly \$5,000 and received more than 100,000 views on HDSA's YouTube channel.



#### Athletes vs. HD

HDSA's first **Athletes vs. HD online auction** in May generated a ton of awareness in the sports world and raised more than \$2,600!

#### William H. Macy Hosts Virtual Bourbon Tasting Event to Support HDSA

On June 17<sup>th</sup>, stage and screen star **William H. Macy** hosted a virtual bourbon tasting event to support HDSA which raised more than \$31,400!

William H. Macy



#### New York City Marathon Team Raises More Than \$64,000

Eighteen runners from across the United States participated in the 50<sup>th</sup> Anniversary running of the **TCS New York City Marathon** and helped raise more than \$64,000 to support the Huntington's Disease Society of America.

"We can't thank our runners enough for all their hard work to not only fundraise, but also for their willingness to take on the NYC Marathon to support

Randell Hansen, 2. Paige Stafne, 3. MaryAnn Emerick,
Ken Nadsady, 5. Andrew Bliss, 6. Samantha Cox,

the fight against Huntington's disease," said HDSA's
President and CEO Louise Vetter. "Each step they
took through the five boroughs was a tribute to
the strength of the HD community and helped
to raise awareness for this devastating, rare
brain disease."

In addition to the generous donors supporting the HDSA runners, participation in the TCS New York City Marathon was made possible in part by sponsorship from **Eisner Amper LLC**.



FREEZE HD

>\$212,000

RAISED FOR HDSA

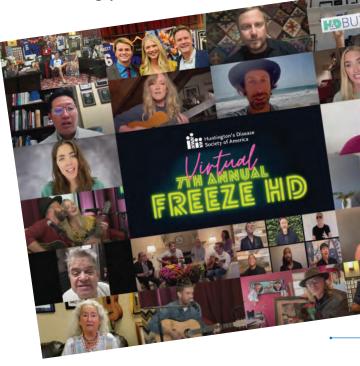
On Saturday, October 16<sup>th</sup>, the stars came out to support the Huntington's Disease Society of America at the **Seventh Annual Freeze HD** event. Hosted live from Los Angeles by **Kate Miner, Scott Porter** and **Jason Ritter,** more than \$212,000 was raised to support HDSA's mission to improve the lives of families affected by Huntington's

> disease, a rare, inherited brain disease.

"Being virtual for the second straight year, allowed Freeze HD to share the story of HD families to a global audience while generating much-needed funds to support HDSA's support programs," said HDSA's President and CEO **Louise Vetter.** 

"It was a special night for HD families, and we are grateful to all who donated, sponsored, and performed and to our incredible hosts Kate, Scott and Jason for putting together an amazing show."

To learn more about Freeze HD, please visit HDSA.org/freezehd.





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#### **2021 FREEZE HD SPONSORS**

#### GOLD SPONSOR uniQure

SILVER SPONSORS Fade Into The Bright and Milkman/Marron Foods

#### **BRONZE SPONSORS**

Tammy & Jessica Cain, CPM, Fake Empire, Kelsey & Scott Porter and The Sypek Group

#### BAR SPONSORS

After Hours Theatre Company, Gersh Agency, Philip Koosed, The Impact Agency, Rotary Club Studio City-Sherman Oaks, Torn2rbns Productions Inc and Twelve Rivers Realty

#### **FRIEND SPONSORS**

Big Yellow Dog Music; Boothatron Solutions; Brillstein Entertainment Partners; Nassif Dow; Force Environmental Inc.; Lazarus, Goldbarg & Associates; Theresa O'Hern; Pathfinder Partners; Laurayne Ratner; Carly Ritter; Alyssa Schwartz; and Eric & April Williams.

Thank you to the Freeze HD committee for all their hard work and commitment to making Freeze HD a success:

Jessica Cain, Kipenzi Chidinma, Blake & Jenne Coler-Dark, David Cooper, Brian Logan Dales, Christopher & Lisa Davis, Jessica Etting, Matt & Courtney Hamilton, Gentille Koosed, Justin & Kate Miner, Marianna Palka, Scott & Kelsey Porter, Carly Ritter, Jason Ritter and Alana Yankowitz.

### Virtual 36<sup>th</sup> Annual HDSA Convention Welcomes Thousands from Around the World

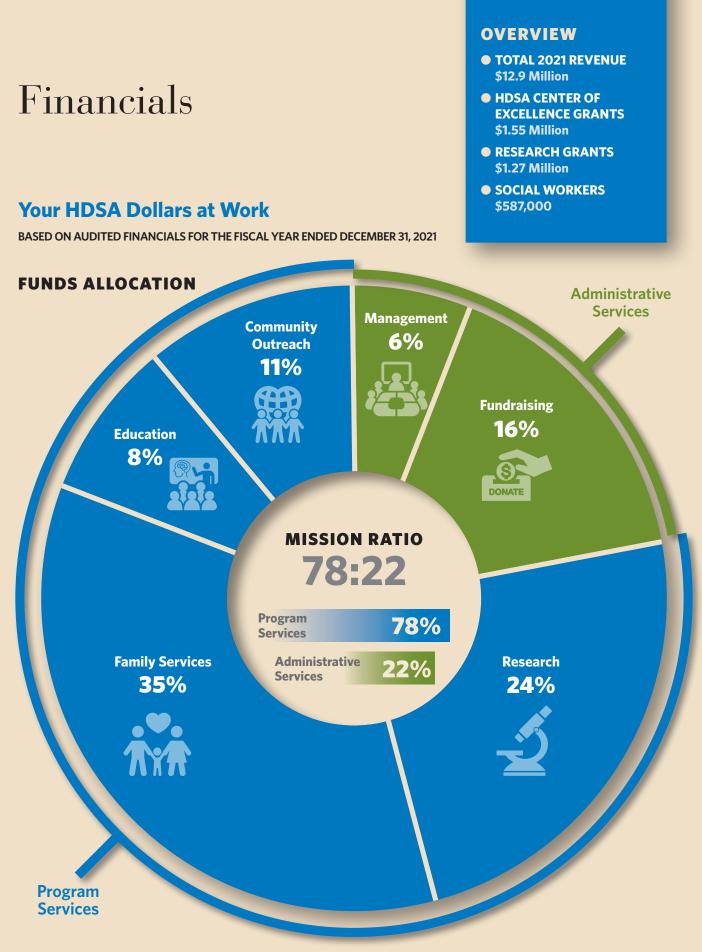
Nearly 2,100 registrants from more than 33 countries participated in the Virtual 36th Annual HDSA **Convention** June 10<sup>th</sup> to 13<sup>th</sup>. The four-day virtual event featured world-class presentations on the latest in Huntington's disease research and care. Despite not being able to meet in-person, the Virtual HDSA Convention allowed guests to connect virtually through the HDSA Convention app and visit the Virtual Exhibit Hall.

Huntington's Diseas Society of America

Huntington's Disease Society of America **HDSA NATIONAL AWARDS PERSON OF THE YEAR AWARD** Yvonne Sweeten **MARJORIE GUTHRIE AWARD** E.J. Garner **WOODY GUTHRIE AWARD** Doug Schulte YOUTH/JHD AWARD Jenna & Gia Mannone VIRTUAL 36TH ANNUAL HDSA CONVENTION JUNE 10-13, 2021 | HDSA.ORG/CONVENTION **CHAPTER OF THE YEAR AWARD** HDSA Illinois Chapter **AFFILIATE OF THE YEAR AWARD** HDSA San Francisco Bay Area Affiliate

> **Recorded sessions from the Virtual 36th Annual HDSA Convention are** available at www.HDSA.org/convention.





### **Statements of Financial Position**

#### AS OF DECEMBER 31, 2021 AND 2020

	2021	2020
SETS		
Cash and cash equivalents	\$ 11,228,810	\$ 9,339,030
Pledges and contributions receivable, net	2,598,770	1,133,748
Investments	2,503,034	2,310,097
Prepaid expenses and deposits	193,969	154,406
Property and equipment, net	28,993	35,148
Website costs, net	18,343	39,529
Total Assets	16,571,919	13,011,958

#### LIABILITIES

Total Liabilities	1,912,477	2,563,066
Obligation under capital lease	<u> </u>	3,734
Deferred rent obligation	103,731	114,721
Paycheck Protection Program loan payable	<u> </u>	634,692
Event revenue received in advance	61,177	17,800
Grants payable, net	1,364,174	1,283,055
Accrued compensation	263,269	294,228
Accounts payable and accrued expenses	120,126	214,836

#### NET ASSETS

Total Liabilities And Net Assets	16,571,919	13,011,958
Total Net Assets	14,659,442	10,448,892
	3,840,665	4,528,085
Perpetual in nature	250,000	250,000
Time-restricted for future periods	2,354,950	99,950
Purpose restrictions	1,235,715	4,178,135
With donor restrictions		
	10,818,777	5,920,807
Board-operating reserve	1,808,203	1,805,969
Undesignated	9,010,574	4,114,838
Without donor restrictions		

**NOTE:** These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

### **Consolidated Statements of Activities**

### YEAR ENDED DECEMBER 31, 2021 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2020

	2021	2020
SUPPORT & REVENUE	( 005 000	2446.252
Public donations	6,095,983	3,116,252
Foundation grants and corporate contributions	2,330,828	3,115,452
Federated campaign	244,545	246,913
Special events (net of direct benefit to donors of \$212,622 and \$618,196 in 2020 and 2019, respectively)	3,361,360	2,254,487
Investment (losses) earnings, net	9,661	21,904
Donated services and materials	173,753	132,439
Gain on Paycheck Protection Program loan forgiveness	634,692	
Other income	87,656	83,178
Total support and revenue before net assets released from restrictions	12,938,478	8,970,625
Net assets released from restrictions		
Total Support and Revenue	12,938,478	8,970,625
Program services: Research	2,052,914	2,102,371
Family services	3,005,423	3,083,605
Education	704,513	761,119
Community outreach	972,726	1,023,900
	6,735,576	6,970,995
Supporting services:		
Management and general	570,858	592,598
Fundraising	1,421,494	1,217,994
	1,992,352	1,810,592
Total Expenses	8,727,928	8,781,587
Change in net assets	4,210,550	189,038
Net assets - beginning of year	10,448,892	10,259,854
Net Assets - End of Year	14,659,442	10,448,892

**NOTE:** These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA

National Office for a full copy of the audited financial statements.

## Thank You HDSA Donors!

#### Thank You to Our Donors for Their Generous Support of HDSA With \$1,000 or More

Anonymous (6) Ms. Greta K. Abbott Mr. & Mrs. Robert Abbott Ms. Kim Adams Mr. James Agnich Ms. Jessica Aguilar Mr. Caesar Alaienia Mr. Kamran Alam Mr. Jeremiah Alexander Mr. & Mrs. Bernard Allen Mrs. Brenda Allen Mr. & Mrs. Wade Allred Mr. Mordecai Alpert Ms. Amy Anderson Mrs. Claudia Anderson Ms. Jenn Anderson Ms. Joanna Anderson Mr. Jonathan Anderson Mrs. Margaret Anderson Mr. Paul Andriot Mr. Levi Arel Ms. Agnes M. Arnold Mr. Richard Atherton Ms. Diane Atkins Debbie & Paul Augustad Ms. Lucinda Ayers Mr. Michael Ayers Dr. Sand Bagoon Ms. Koaki Bailev Harris Mr. & Mrs. Marshall Baker Ms. Sherry Baker Mr. Timothy Baker Ms. Toria Baker Ms. Bonnie J. Baldwin Mr. Norman Baldwin Ms. Jacqueline Ballwanz Mr. Chandler A. Barbour Mr. Larry Barnhart Ms. Stacey Barton Ms. Kathleen Bates Ms. Marylee Battaglia Ms. Alice Bean Ms. Caroline Becker Ms. Linda Becker Mr. Brett Begemann Dr. Ashok Behl Mr. Andrew Bell Ms. Kristy Benner Ms. Mary Jeanne Benner-Knopp Ms. Gudrun S. Bennett Mr. Justin Bennett Ms. Kim Bennett

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